

Testimony of Linda Zani Thomas of The Parents Group requesting \$2.7 million dollars for a state funded grant for the creation of medical special needs day programs

Hi, I'm Linda Zani Thomas founder of The Parents Group, a group of advocates for the smallest skew of adults with developmental disabilities: those with medical conditions and sometimes severe physical and sensory ailments. Our children are designated as a Level 5-6 by DDD—there is no Level 7. **We learned last week that despite our best efforts, DDD will not be allocating any funds for vans and equipment needed to create medical day programs for the medically fragile population graduating in four months. We are asking you to allocate an additional \$2.7 million dollars to the DDD Budget in the form of a grant so medical special needs day programs can be created for 120 2014 graduates.**

Now, who are Level 5-6 people and why is this so important?

There are only 505 families in our state that are raising these young adults at home. There are 2,304 in New Jersey, most living in Nursing Homes or Developmental Centers or other state-run facilities. It is universally thought that living at home with an intact family that is financially and emotionally stable is best. Families like ours are striving mightily to keep their loved ones at home and not to have to place them elsewhere. We all need one thing: a safe, stimulating healthy day program for our young adults, with transportation because most of our children are in wheelchairs and many families cannot afford adapted vehicles to transport them. This allows the young ones the opportunities for growth and stimulation they need, and it allows working families to keep on working.

There is both a capacity and a quality problem in regards to day programs for the medically fragile in New Jersey. **Simply put, we need you to allocate 2.7 million dollars so all those graduating this year will have a safe, stimulating place to go to. Without these funds, families will be forced to place their loved ones in unsuitable situations and/or to quit their jobs and keep them at home. This will lead to a path to placing more people at developmental centers.**

After the graduating class of 2010 was face with this exact situation four years ago we vowed we would do everything we could so it would not happen again. But here we are. It took us over 3 years to convince DDD of the need for a new program. We secured partial state funding and worked with Community Options Inc. to create the Red Ribbon Academy day program in Wayne. It opened one year ago and within four months was

full. Families waited for up to 7 years to finally place their medically fragile adult children at Red Ribbon Academy, and many came in after being neglected or physically hurt in other programs.

There is now a waiting list of dozens of 2014 graduates who would like to attend a program of the caliber of the Red Ribbon Academy. Many families want to move their young adults from poor quality programs but cannot. The programs they like are all full, and the providers cannot create new programs because they do not have money for vans and equipment.

What are Best Practices in a Level 5-6 Medical Special Needs Day Program?

The Health Care Financing Administration (HCFA) revised their standards in 1996 to focus on four conditions of participation at ICF/DDs. These Key Performance Indicators are also needed at Medical Special Needs Day Programs.

Active Treatment: assessing what individuals are capable of doing, to help them maximize their potential, and to do so with professionalism and compassion. This comprehensive approach to helping individuals acquire the skills necessary to "least restrictive" living is the basis of Active Treatment.

Client Protection: Policies and procedures necessary to prevent neglect or abuse.

Client Behavior: Positive behavioral reinforcement techniques, aka Gentle Teaching.

Healthcare Services

In the opinion of parents of Level 5-6 Adults in North Jersey, only four DDD Day Programs that hit all 4 KPIs exist, none have vacancy, all have waiting lists to get in and clients want them to expand/ replicate. None of the four have committed to doing so as of 3/3/14. The providers cite lack of start up funds for vans and equipment as the reason they will not create new day programs---even though dozens of families have asked them to.

What happens when Level 5-6 young adults attend quality day programs?

At Red Ribbon Academy:

*In some cases, their vision has gotten better. In particular, Marissa Allen tracked light for the first time in the sensory room.

* Their communication skills have had a steep uptick. Clients who barely spoke before are speaking, those who did are adding new words, and everyone is learning American Sign Language, one gesture at a time.

* They are accessing technology, via iPhone and iPad apps and the Kindle. This is highly motivating and the staff has been weaving in OT goals. For example, Mark Poalise is holding the phone with one hand and using his weaker left hand to scroll the screen.

* Everyone is moving a lot more, even those in wheelchairs. This has led to many people needing wheelchair adjustments.

* There has been impressive weight gain among the clients. They are enjoying eating together and learning to cook and prepare foods. This is important because it will help them survive their next illness or surgery.

* There have been academic achievements such as increased science knowledge like Mo.

* And major gains in social skills, most notably in fine dining, dancing, table manners and purchasing and tasting the wines of Italy (this last one by Mo at home!).

* The more able individuals are also looking after the others, with Christina holding Jillian's hand on the bus, Laura assisting others with games, Mo reading Cat in the Hat to those who cannot read and those first in in the morning greeting the others as they arrive.

Thank you for listening and please add \$2.7 Million to the DDD budget in the form of a state funded grant that can then be accessed by quality providers to create medical special needs day programs for 120 2014 graduates.

Issue #1: There is a lack of awareness of New Jersey's Level 5/6 population in general, what they need in order to live a quality life in the community, and a lack of understanding of what they can achieve. This is most likely due to three factors: the extremely small size of this group with most not living in the community, lack of organized advocacy, and lack of measurement and identification.

Currently this population is defined by their diagnosis or combinations of conditions (CP, MR, Blind, Deaf, Epilepsy), by their lack of function in three or more of the seven Major Life Activities (self care, language, learning, mobility, self-direction, independence, economic sufficiency), or by catchall phrases, as listed below:

- Multiply disabled
- Severe, Chronic Disability (E. Boggs)
- Level 5/6 via DDRT
- Individuals with developmental disabilities with a high acuity of medical needs
- "the Waiver crowd"
- "Not Employment First"
- "Very involved"
- Medical Special Needs population
- The "smallest skew"

This group of 2,304 individuals "meets the level of need for ICF/DD services".

Solution: Identify this group of 2,304 individuals with a short, descriptive name, and take the lead nationally in measurement and tracking.

* Rename this group "Individuals with Exceptional Needs" and educate the public about them.

* Take the lead nationally in measuring and tracking of this cohort by sharing New Jersey's DDRT Level 5/6 categorization method with other states and national organizations, including the National Core Indicators project and encourage them to analyze this subgroup across the states they serve.

* Measure family outcomes and satisfaction and track effectiveness of the initiative in NJ in 2014, with a national rollout in 2015

Issue #2: The Exceptional Needs cohort in New Jersey is significantly less likely to be living at home or in the community than individuals with lesser conditions: only 22% live at home vs. 70% of the general developmentally disabled population. 44% live in Nursing Homes, 17% in developmental centers, and 2% have been placed out of state. Another 15% live "in the community", most in DDD funded residences of 16-100 individuals such as Closter Spectrum, Eastern Christian in Wyckoff, and Matheny in Peapack. A limited amount live in group homes of 4 or less individuals, widely considered the ideal for out of home placement.

At-home living is typically preferred by individuals and their families. It is also the most economic option: placement at Developmental Centers costs \$300K+ per year, over \$200K in group homes and over \$100K in nursing homes. Out of state placements may be the most costly of all.

Solution:

1. Create a "Community First" initiative for this group, adopting the UCP Case for Inclusion 80/80 Standard of 80% living in the community and corresponding waiver funding.

2. Provide families with necessary supports to raise these children at home. The constellation of supports and funding amounts include:

*Safe, quality day programs with transportation: \$58,500 Individual Budget

*Extra funds for respite, camp and durable medical equipment: \$15,000 Family Supports

*Comprehensive health benefits comparable to those at Developmental Centers(see issue #5)

*Home health aide help in the mornings and afternoons, if needed

*CRPD waiver for in-home nursing, if needed

3. Measure economic impact of increasing at-home care to 80% and measure family satisfaction and outcomes, including the number of jobs created by Level 5/6 individuals, estimated at between 2-4 jobs created per Exceptional Needs individual. The economic impact of losing these jobs was used successfully by legislators in Vineland to stop the closing of the Developmental Center there.

4. Create purpose-built community housing for this cohort.

Issue #3: There is no turnkey method for families, their support coordinators and their choice of quality provider to create new day programs for the Exceptional Needs population. Start up funds for facility build out, transportation and equipment total \$536,000 per 25 person program and cannot be attained by providers or through family fundraising. These funds cannot be funded as a match through the Medicaid fee-for-service funding model.

Solution:

- * Get \$ 2.7 Million in state dollars for the creation of 5 new day programs to serve 120 Exceptional Needs individuals graduating in 2014, transferees from other programs, and those entering the community from Developmental centers and 'I Choose Home'.
- * Create a vetting process for granting of these funds that includes representation from Exceptional Needs families in the RFP process.
- * Create a method for families and Support Coordinators to facilitate creation of new day programs with providers of their choice.

Issue #4: Quality of some existing day programs is suboptimal. Families are reporting dangerous situations posed by clients with aggressive behaviors housed in close quarters with little to no supervision in the same day programs. Some medical special needs day programs have old facilities in poor to fair condition, dilapidated vans and equipment. Others are reporting lack of programming and neglectful situations due to mismanagement. Families who have filed complaints and go through the DDD incident reporting process have no way of knowing the outcome.

Solution:

- Raise Exceptional Needs Day Standards
- Monitor programs and have sanctions for those who do not meet the standards.
- Do not allow individuals with aggressive behaviors to be cared for in the same quarters as the Exceptional Needs population.
- Create more transparency and family interaction with the DDD incident reporting policy process and its conclusions. Families of those currently attending suboptimal programs must be empowered to facilitate changes in those programs in accordance with new day program standards, or be able to take their Individual Budget of \$58,500 elsewhere.

Issue #5: After age 26, families must rely on Medicaid HMO insurance only for their adult children with developmental disabilities. More than 40% of physicians will not accept Medicaid and many hospitals will not take Medicaid either, resulting in lack of continuity of care and lack of choice. Out of pocket costs are high for equipment, treatment and hospitalization. According to the NCI Data Brief of 11/10, in a survey of the general developmentally disabled population, " individuals who lived at home were less likely to have had a physical or ob/gyn exam in the past year or dental exam in the past six months as those who lived away from home"

Solution:

Attain the same level of healthcare benefits as those at the developmental centers and ensure that families have transportation to necessary appointments.

Facts About Level 5-6 Adults

1. Level 5-6 adults receive annual state funding in amounts that vary from \$0 to \$310,000+ depending on:

Where they reside:

- * At ICF/DD: \$310K; at home \$0; group home: \$190K
- If they live out of state: \$280k+

What They Do During the Day:

- If they attend a day program and live at home: \$26K-\$47K
- If they are on Real Life Choices: \$70k+
- If they self direct day services: \$26K
- Many are at home receiving no services : \$0
- Some receive day services at ICF/DDs

If they qualify for Medicaid

- Those not qualified must private pay for day services

If they are on the CRPD waiver and receive state funded nursing (\$156k+)

- * Those on this waiver must either private pay or accept Medicaid daycare

2. Services for Level 5-6 Adults in New Jersey at the developmental centers (ICF/DD) cost \$280-310K per person annually. Level 5-6 adults are "entitled to ICF/DD Level of care".

Mandated services at ICF/DD include:

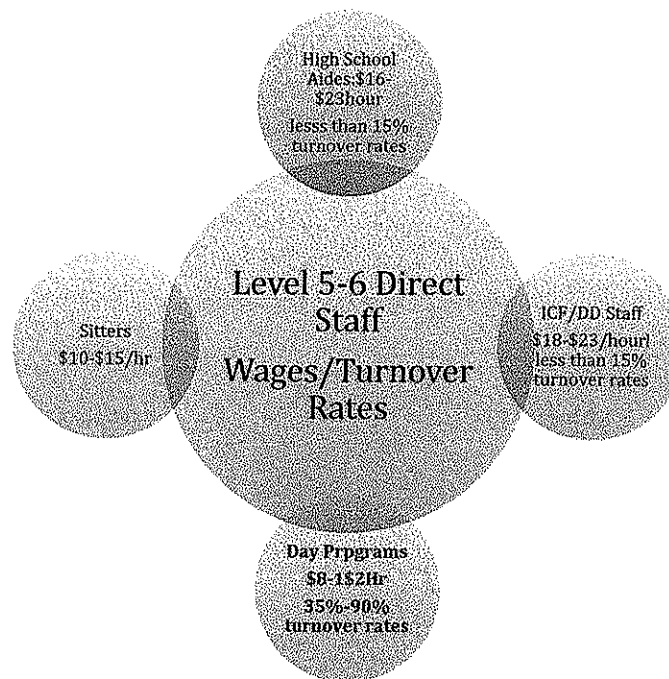
- Quality Assurance and Oversight: Medicaid Conditions of Participation far superior to Community Group Home oversight.
- Active Treatment at Residences and Day Programs: This philosophy drives therapies, medical treatment, direct care and habilitation
- Medical Supports: Long term Medicaid at ICF/DDs superior to HMO Medicaid, access to MDs/HCPS far superior to those at home or in community.
- Continuity of Care: Turnover rate is directly related to direct staff wages, ICF/DDs pay wages of \$18-23

3. Quality and Continuity of Care is Extremely Important for Level 5-6 Adults.

Forbes magazine has cited that annual turnover rates under 15% are acceptable and the best companies in the US have rates under 3%. Turnover rates at some group homes and day programs are upwards of 30%- some have been reported at 90%.

Best practice for direct staff wages are at the centers--\$18-\$23/hr. Those rates are also those paid by school systems for aides for the very same population: \$20-23/hr. Same exact job as direct staff at day programs and residences, currently making \$8.75-\$12.

Same Job /Different Wages:



According to a 2001/2002 maxassociation survey (www.maxassociation.org/surveyreport.pdf) in terms of nonprofit direct care staff retention/turnover:" Higher wages correlated with better recruitment and retention measures". Also, they found that "Agencies that paid ... higher showed dramatically lower turnover and vacancy rates".

4. Level 5-6 Adults living at home or in group homes are having a healthcare crisis, receiving substandard medical benefits vs. their peers at ICF/DDs.

Over 40% of Primary Care MDs in New Jersey do not accept Medicaid. Of those who do, 54% will not accept new patients. NJspotlight.com

Physicians cite too much paperwork and low reimbursement rates as reasons. MDs are reimbursed only \$23 per 45 minute appointment for those with complex chronic medical needs, such as Level 4 adults. Physical Therapists are reimbursed \$7 per hour, with their regular rate at \$95.

5. The Health Care Financing Administration (HCFA) revised their standards in 1996 to focus on four conditions of participation at ICF/DDs:

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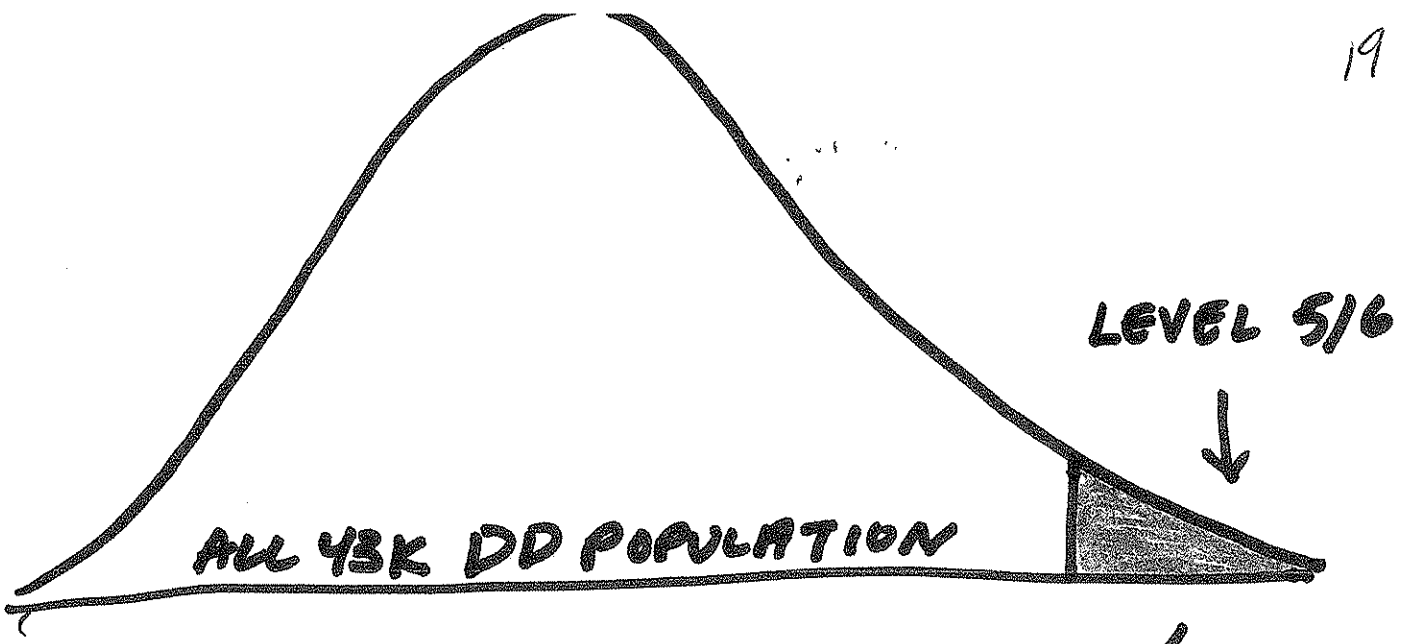
Client Protection: Policies and procedures necessary to prevent neglect or abuse.

Client Behavior: Positive behavioral reinforcement techniques, aka Gentle Teaching.

Healthcare Services

6. Capacity and Level 4-6 Day Program Options in Bergen/Passaic County by HCFA Key Performance Indicators (KPIs)

In the opinion of parents of Level 5-6 Adults in North Jersey, only four DDD Day Programs that hit all 4 KPIs exist, none have vacancy, all have waiting lists to get in and clients want them to expand/ replicate. None of the three have committed to do so as of 10/3/13.



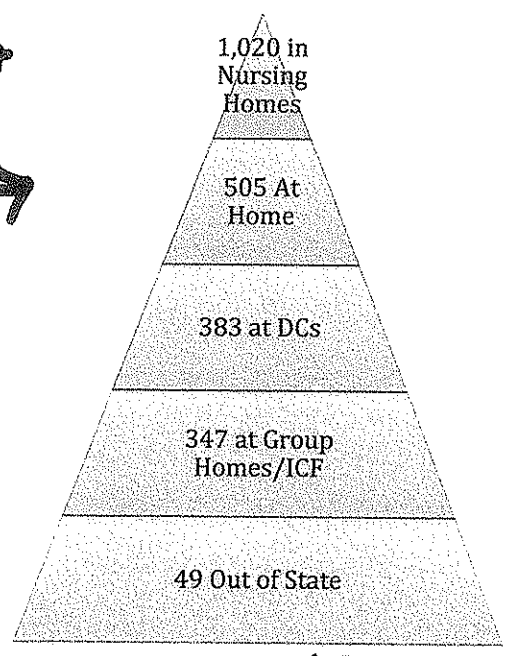
"BEST PRACTICE" COST
 \$100K⁺

x \$0 →

\$300K⁺

\$200K⁺

\$300K⁺



N = 2,304 LEVEL 5-6